

State Newborn Screening Status, Core Conditions, January 23, 2007

State	Births	% of US Births	Conditions Screened	Remaining Conditions*	Count of 'C' Conditions
Colorado	68,503	1.7%	29	---	0
District of Columbia	7,933	0.2%	29	---	0
Iowa	38,438	0.9%	29	---	0
Kentucky	55,720	1.4%	29	---	0
Maryland	74,628	1.8%	29	---	0
Mississippi	42,827	1.0%	29	---	0
New Jersey	115,253	2.8%	29	---	0
New Mexico	28,384	0.7%	29	---	0
Rhode Island	12,779	0.3%	29	---	0
Virginia	103,933	2.5%	29	---	0
Wyoming	6,807	0.2%	29	---	0
Alaska	10,338	0.3%	28	CF (Not Testing)	0
Connecticut	42,095	1.0%	28	CF (Select populations or by request)	0
Delaware	11,369	0.3%	28	CUD (Not Testing)	0
Florida	218,053	5.3%	28	CF (Required/Not Implemented)	1
Georgia	138,849	3.4%	28	HEAR (Universally Offered/Not Required)	0
Hawaii	18,281	0.4%	28	CF (Not Testing)	0
Illinois	180,778	4.4%	28	CF (Not Testing)	0
Indiana	87,142	2.1%	28	CF (Not Testing)	0
Louisiana	65,369	1.6%	28	CF (Not Testing)	0
Minnesota	70,624	1.7%	28	HEAR (Universally Offered/Not Required)	0
New York	249,947	6.1%	28	TYR1 (Not Testing)	0
North Dakota	8,189	0.2%	28	HEAR (Universally Offered/Not Required)	0
Ohio	148,954	3.6%	28	TYR1 (Not Testing)	0
Utah	50,670	1.2%	28	CF (Not Testing)	0
Vermont	6,599	0.2%	28	CF (Not Testing)	0
Wisconsin	70,146	1.7%	28	HEAR (Universally Offered/Not Required)	0
Arizona	93,663	2.3%	27	---	1
Idaho	22,532	0.5%	27	---	0
Missouri	77,765	1.9%	27	---	2
Nevada	35,200	0.9%	27	---	0
South Carolina	56,590	1.4%	27	---	0
South Dakota	11,338	0.3%	27	---	0
Tennessee	79,642	1.9%	27	---	0
California	544,843	13.2%	26	---	2
North Carolina	119,847	2.9%	26	---	0
Texas	381,293	9.3%	26	---	1
Maine	13,944	0.3%	24	---	0
Oregon	45,678	1.1%	23	---	0
Alabama	59,510	1.4%	19	---	0
Massachusetts	78,484	1.9%	12	---	0
Michigan	129,776	3.2%	12	---	0
New Hampshire	14,565	0.4%	12	---	0
Washington	81,747	2.0%	12	---	0
Nebraska	26,332	0.6%	10	---	0
Oklahoma	51,306	1.2%	10	---	0
Pennsylvania	144,748	3.5%	9	---	0
Arkansas	38,573	0.9%	7	---	0
Kansas	39,669	1.0%	7	---	0
West Virginia	20,880	0.5%	7	---	0
Montana	11,519	0.3%	6	---	0

*Conditions only listed for states currently screening 28 conditions.

Source: National Newborn Screening and Genetics Resource Center,
National Center for Health Statistics, 2004 final natality data.

Prepared by the March of Dimes Perinatal Data Center, 2007.

Testimony for Senate Bill 162
Monday, January 29, 2007
Helena, MT

My name is Debra Donovan. I am the Director of Program Services for the Montana Chapter of the March of Dimes Foundation.

I am here today representing the March of Dimes and its mission to improve the health of babies by preventing birth defects, premature birth and infant mortality. March of Dimes strongly supports Senate Bill 162 to expand newborn screening in Montana. Senate Bill 162 is very important in order to detect early in an infant's life, 28 disorders that may cause life threatening and debilitating conditions. Science has enabled the medical profession to identify through a blood screening which babies need to be treated to save their lives or limit the disabilities that they may have.

I was new to the March of Dimes early last year and had the opportunity after being on the job only 3 days to participate in the Task Force to study the issue of expanded newborn screening. In a room with the most informed, intelligent and public policy dedicated professionals, it became very apparent to me that expanding our current newborn screening panel is the only community and public health-conscious decision that could be made.

At times some of the language that these medical professionals used (that many times had words with 16 syllables, I swear), was more than I could comprehend, but the message was very clear: **screening for the 28 disorders and hearing can help to prevent mental retardation, severe physical disabilities and even death for children born with these conditions.**

The problem is that each state or region in the United States designs and operates its own newborn screening program, and, unfortunately, these programs can vary widely in the number and type of conditions for which they screen. As you can see on the graph with all fifty states represented, Montana is among only 7 states that tests for 10 or less. In fact we are at the very bottom of the list. How can we be the poorest at providing a healthy chance for newborn babies when most of us believe that Montana is truly the best place to live and raise our families? Currently, our state requires tests

for only 6 metabolic conditions plus hearing. A baby who is born just across the border in Wyoming will be tested for all 29 disorders and will have a chance to a productive life if the disorder is diagnosed and treatment was to begin early. Babies born in our neighboring states of Idaho, North Dakota, and South Dakota also get screened for the majority of the disorders in the core panel. That's not the case in Montana. This is not acceptable to the families in our state who may be unaware of the tests available but not required by our state. It should be a privilege to be born in the state of Montana, not a burden.

The March of Dimes support the recommendations made by the experts to require newborns to undergo the full panel of 29 genetic and metabolic tests recommended by the American College of Medical Genetics and endorsed by the American Academy of Pediatrics and the March of Dimes. Senate Bill 162 will also establish a program of comprehensive follow-up services, including education and counseling, for newborns and parents of newborns identified with disorders

On behalf of the March of Dimes, thank you for the opportunity to voice our strong support for Senate Bill 162 which would allow the state of Montana to expand newborn screening to save lives.

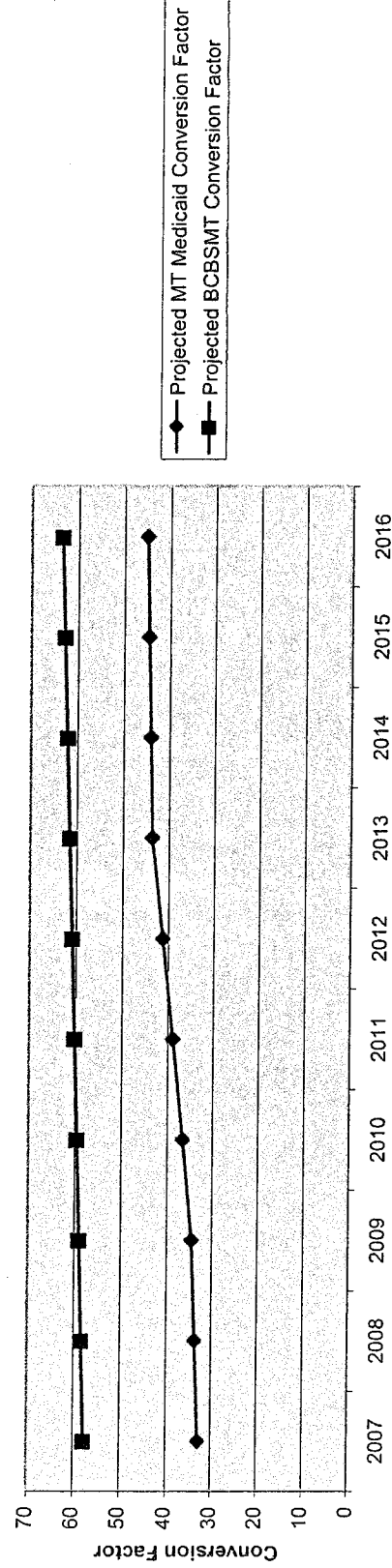
MONTANA MEDICAL ASSOCIATION

March 12, 2007

Pat Melby 442-7450

Year	Projected MT Medicaid	
	Conversion Factor	Projected BCBSMT Conversion Factor
2007	32.81	57.7
2008	33.63	58.28
2009	34.47	58.86
2010	36.53	59.45
2011	38.72	60.05
2012	41.04	60.65
2013	43.5	61.26
2014	43.93	61.87
2015	44.37	62.49
2016	44.82	63.12

Comparison of Projected MT Medicaid and BCBSMT Conversion Factors Through 2013



Notes:

Projected MT Medicaid Conversion Factor (CF) was calculated based on 2.5 % increase for 2008 and 2009 and 6% increases for each year from 2010 - 2013 as published in SB0354.02

For the projected BCBSMT CF, an average increase was first calculated from 2004-2007. That 1.01% average increase was then applied to each year from 2008 - 2013.

In 2013, the projected MT Medicaid CF is 71% of the BCBSMT projected CF. This same 71% ratio was applied to the Medicaid CF from 2014 - 2016 based on the continuation of the 1.01% increase in BCBSMT's CF for the same years.

For testimony on newborn screening
Philip Pallister, MD

In 1973 I prepared a Chronological Brief Regarding Biochemical Screening of Newborns As It Pertains to Montana which outlined the whole business, and that **we were then screening for twenty-three genetic diseases** (fifteen amino acids, six mucopolysaccharidoses, & two sugar disorders) cheaper and more accurately than the state was doing for PKU alone and that we could screen for T3 & T4 (two thyroid tests) for an additional \$3.43 per patient. Nine of the AA and sugar conditions were treatable then, some of the MPS disorders were possibly treatable while eight or nine of the thyroid conditions were all treatable. In addition RH and blood type conditions and rubella problems could be prevented. The state had missed about seven genetic disorders from 1959 to 1965 that we knew how to screen and to treat.

We had a list of all the cases identified:

PKU	-	34	
? Homocysteinuria	-	2 *	
? Hyperprolinemia	-	1 *	
Mucopolysaccharides	-	8 *	
Hypothyroidism	-	18 *	
Rubella syndrome	-	14 *	
Kernicterus	-	15 *	*All of these patients were in Boulder

It was costing the state \$35,000 a year to treat and care for such patients then and their life expectancy was about 50 years. We could do all of these tests for \$4 per patient on the 11,00 Montana newborns - \$45,000 per year. We had done over 2000 such newborns in Boulder and Helena to demonstrate the efficacy of screening. I don't know the actuarial figures today but they are certainly proportional.

Last year I looked at the list of retarded (developmentally disabled - whatever that means?) patients in Boulder. There were 79. Only 21 carried a diagnosis. There was no admission screening, chromosome lab or genetic lab, etc. Some of the missed patients are scattered around the state in other settings.

There are at least two states screening for 50 disorders; Mississippi is one. Montana once led the nation. Now it is near the bottom!

Today the situation is much the same. We are missing patients and not identifying families that can be helped! It is costing us dearly!

Finding and treating one patient a year is sound economics for those interested in money.

I prefer to think of the social and human wastage that occurs from our neglect.

Newborn screening in Montana
Philip Pallister, MD

- 1934 The first "inborn error of metabolism" – phenylketonuria (PKU) was described by Fölling, a Norwegian chemist – he published 11 cases.
- 1940 Jervis, Letchworth Village, Thiells New York, proved PKU was a recessive disorder inherited from both parents; in 1947 he demonstrated these patients could not metabolize an amino acid essential for brain formation (phenylalanine); in 1953 he demonstrated these patients had an inactive enzyme, phenylalanine hydroxylase, in their livers so they could not metabolize and use phenylalanine. **He proved that the problem was inherited from each parent as a defect in metabolism and located the problem in a liver enzyme.**
- 1956 Three years later I met George Jervis in Richmond, VA, returned to Boulder where we screened 500 patients using Fölling's method, dropping a few drops of 10% ferric chloride in acidified urine, or on a diaper, leading to a deep blue color in PKU patients - the "diaper test." There were four patients in Boulder (two were sisters), four in their relatives, three on the waiting list and one in Warm Springs State Hospital for the insane – twelve in all.
- Armstrong and Tyler at the new medical school in Salt Lake determined the brain damage was mostly caused by high levels of un-metabolized phenylalanine in the blood and were using a diet low in phenylalanine created at the U of Indiana called the Basal Mix diet. We began to treat a patient from Flaxville with their help. Her resulting IQ was in the sixties. Four of her relatives with PKU were less than IQ 30. The Ketonil diet came out in '56 followed later by Lofenalac
- 1959 In Hartford, CN, as a Fellow of the American Association on Mental Deficiency (AAMD, now called AAMR and soon to be AAIDD) and on the five member planning committee, **I proposed we push for national screening using the diaper test after the newborn has had one meal or more of milk.** The other physician on the committee, very senior and head of the Faribault, MN institution, blocked it – "since no treatment was available." **I returned to Montana and as the only GP on the Montana Medical Association's Maternal and Child Health Committee I made the proposal we screen in Montana: the five pediatricians and the five obstetricians voted against it using similar reasoning.**
- Al Miller (Helena pathologist) and I began to do free of charge newborn screening at St. Peter's Hospital and Boulder and helped other hospitals set up their programs. Most of the testing was in Boulder

In the meantime 1/10-12,000 newborns in all of Montana were being missed!

Legislative Efforts

Very few physicians and others were interested in screening newborns for these rare diseases but **in 1965 the Butte Parent's group, with our stimulus, had SB 128 introduced by Senator R. T. O'Neill from Roundup with Reardon from Butte, Dessault from Missoula and others and it became law (Chapter 108, 39th Legislative Assembly).** The law was on the books but bureaucratic failure led to no oversight and little statewide testing occurred.

In Dillon, two successive infants with PKU were born to a young dentist and his wife in the Barrett Hospital and were finally diagnosed by Roger Clapp, a Butte pediatrician familiar with our efforts. Doctors around the country were being sued for not doing follow-up family studies, etc. and the dentist contemplated suing the state Department of Health but he moved to California.

1971 **Greg K. was born in Helena, tested positive, and was under treatment on his third day of life, several days before the state screening test was reported from Oregon. His mother told me his latest IQ was 117.**

1973 **Dr. Miller and I were testing for 24 disorders and I had recognized that hypothyroidism was as large a threat in Montana as PKU, had set up several methods for testing for that disorder and was convinced we could test newborns. Dick Welch, a pediatrician at the Department of Health and Chief of the Maternal and Child Health Division, and I sat in the dining room at the Boulder institution's hospital in the fall of 1972 and wrote three bills to enlarge our screening program state wide. They were introduced by Gary Marbut from Missoula and others.**

The newborn screening bill first included an **advisory committee** of a parent, pediatrician, geneticist and two others but was removed by the Legislative Council before introduction as not in accord with the new 1972 constitution. John Anderson, MD, head of the Department of Health, said he would form such a committee but he "dragged his feet" -his statement - for over nine months.

David Lackman, a Ph D microbiologist and head of the Department's lab, had vigorously opposed the idea of screening for hypothyroidism from early in 1972, had solicited many national leaders, from Massachusetts and NIH and others, for their supporting views, circularized each doctor in the state with these documents supporting his belief, and as late as April of 1974, Lackman was still avoiding implementing a test for hypothyroidism when he circularized (11 Jan 74) the opinion that their advisory group felt that a newborn test would be negative and should not be done unless there was jaundice for more than 4 days. Most cretins are not jaundiced that early, some not for months. At that time our law required the head of the lab be an MD pathologist; when I pointed this out the law was changed to accommodate Lackman.

Robert Guthrie of the Guthrie tests for PKU and other disorders, as a reaction to Lackman's continuing opposition to hypothyroid screening, called me re a letter of Lackman's asking for Guthrie's opinion. Guthrie cited two places (eg Montreal) where it was working and then he, geneticist John Opitz from Wisconsin and myself met with department personnel (Anderson, et al) as late as 9 Jul 75 and seemed to get nowhere. I do not know when the state finally picked up on the program to stop the development of cretinism in our newborns, but it was sometime later.

With this background it is obvious that I do not trust many bureaucrats, especially senior ones, and even some physicians to do what is right and honorable, to act as the scientists and doctors they should be. I moved from the state job in Boulder, started the Shodair genetics unit and was there for six years when I finally retired.

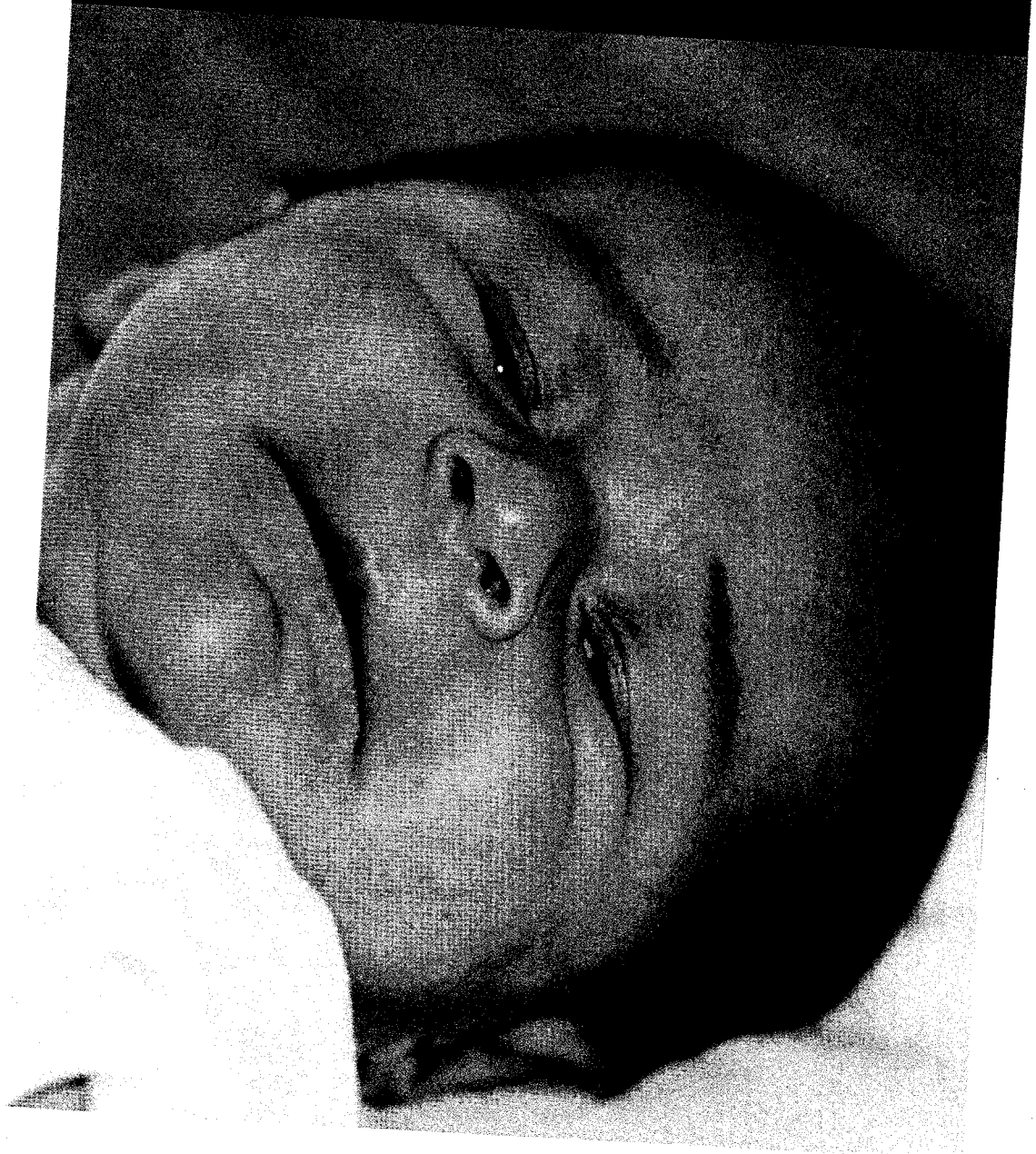
Last spring, much to my chagrin, dismay, watching the Today show, I learned that **Montana was screening for only four disorders although hypothyroidism was one**. What had happened to the 24 tests we had developed and left for them? Al Miller had demonstrated we could do it for about \$1.60 per patient with another \$3.60 for two hypothyroid tests? Jack Casey, now the Shodair Administrator, is also a registered medical technologist and was running our lab in Boulder and doing the testing. We were leading the nation!

Now we have a new chance to take our place with the other informed and progressive states. Two are screening for fifty. Many persons still do not believe in testing if there is no good treatment (as was once the case for PKU), but this forsakes those families that need counseling after the birth of one affected child who are often not diagnosed for many months. We have missed kids with these disorders and for this I am sorry and I feel a need to apologize for my dereliction of responsibility in this area. The legislators do not need to apologize; they have always done their part in giving us the law. Those old bureaucrats should be ashamed of themselves.

Nevertheless, a new breeze is blowing and this bill is the result of modern health educators and leaders, nationally and in Montana, who have worked with an excellent group of advisors to bring us into the middle ranks, at least, in this area. I personally wish we were the nation's leader once again!

**These Tests Could Save Your
Baby's Life**

Newborn Screening Tests



Clack, Sib

To: Human Services Committee of the House of Representatives
Subject: Testimony for SB 162 - Sheila Idzerda, MD

From: sidzerda@aol.com [mailto:sidzerda@aol.com]
Sent: Monday, January 29, 2007 10:21 PM
To: Clack, Sib
Subject: Re: Updated information packet for SB 162

I am writing in regard to the newborn screening bill. I spoke with Dr. Marian Kummer at the recent American Academy of Pediatrics meeting where we discussed this new bill. I strongly support the bill to require and support expanded newborn screening in our state. These tests which would be added to the newborn screen are in line with recommendations from the national standards for neonatal testing. Any one of these conditions can generate great medical expenses for the family and potentially threaten the lives of children affected by these disorders.

With the permission of the family involved, I would like to relate the detection and treatment of an illness in two children within the same family. The older boy, CM, now age 4, first started with illness at 6 months of age. Over the subsequent 3 months he had slowly worsening health despite many investigations into the cause of his illness. Finally at 9 months of age he was so ill that he needed emergency transport to Seattle Children's Hospital by plane. He then spent 2 weeks in the hospital. After his disorder was confirmed he returned home, but required many special services for the next year including occupational and speech therapy. He is now doing well. His younger brother JM, now age 2, had the expanded newborn screening. At 7 days of age his screening was found to be abnormal and he was started on appropriate therapy. He was never sick, has not required hospitalization for his disorder and is developing normally. When I asked his mother which of these situations was the better, her overwhelming support was for the early diagnosis. The preservation of JM's good health, the prompt treatment that he received were most important to her. However she does mention the great expense that went into the diagnosis of her older boy CM. Please listen to our state and national experts and assist Montana children and their families to get the timely help that they need. Sheila Idzerda MD

3/15/2007